

**Submission on Health
Information and Quality
Authority's Draft National Data
Set for Standardising Patient
Discharge Summary
Information**

January 2013

Submission of the Irish Human Rights Commission to the Health Information and Quality Authority on the Draft National Data Set for Standardising Patient Discharge Summary Information

1. Introduction

The Irish Human Rights Commission (IHRC) has a statutory remit under the Human Rights Commission Act, 2000 to endeavour to ensure that the human rights of all persons in the State are fully realised and protected. The IHRC seeks to ensure that Irish law and practice reflects best international practice in the area of human rights. To this end its functions include, keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights, and making such recommendations to the Government as it deems appropriate in relation to the measures the IHRC considers should be taken to strengthen, protect and uphold human rights in the State.

In the present instance, the Health Information and Quality Authority (HIQA) has requested commentary on its Draft National Data Set for Standardising Patient Discharge Summary Information (the Data Set). The IHRC welcomes the publication of the Data Set, which sets out ensure that complete, relevant, reliable and valid information regarding a patient's stay in hospital is sent to their primary care healthcare professional in a timely manner, allowing the primary care healthcare professional to continue the medical care of the patient following discharge. The IHRC's comments on the Data Set focus on its concern that the Data Set may not be sufficiently comprehensive to ensure that it meets the needs of specified vulnerable or disadvantaged groups, such as those presenting with suicidal ideation, those that are homeless, persons with an intellectual disability or mental illness, and members of the Traveller community. In addition the Commission considers that the Data Set as drafted only applies to hospital discharges after in-patient treatment, and does not appear to relate to discharges from Accident and Emergency Departments (A&E Departments), or other institutional settings where a person may be under medical care, such as prisons and nursing homes.

The concerns of the Commission in this regard are borne out by a number of policy documents which highlight that particular difficulties pertain to dissemination of information to primary healthcare professionals in order to ensure the provision of appropriate follow-up services for individuals from vulnerable or disadvantaged groups and a number of recommendations have been made in this regard. For instance in *Reach Out: National Strategy for Action on Suicide Prevention, 2005—2014*, the above noted problem is regarded as “especially important following discharge from mental health in-patient services and following treatment for deliberate self-harm.”¹ It identified as an objective, “To improve mental health service provision, especially in the areas of community mental health, pre-discharge

¹ Health Service Executive, (2005). *Reach Out: National Strategy for Action on Suicide Prevention, 2005—2014*. Dublin: Health Service Executive, at p. 31.

assessment from in-patient services and follow up support.”² The Strategy notes that “prisoners are internationally recognised as particularly vulnerable in relation to suicidal behavior and mental health difficulties, due in part to the increased risks associated with incarceration”³ and recommends that action be taken to “implement support services, information resources and staff training to support suicide prevention and mental health promotion in prison settings, for those on remand and for those recently released from prison.”⁴

With respect to the homeless, the Homeless Strategy Implementation Plan identified as a priority, “Improv[ing] effectiveness of discharge planning and its focus[ing] on preventing homelessness for all individuals leaving childcare, hospital and other residential settings, to include identification of housing needs and follow-up supports, through close links with housing providers and community based services (including health and welfare services).”⁵ It recommended such supporting measures as:

“The HSE to put in place appropriate and effective discharge policies/procedures for homeless people being discharged from acute hospitals and mental health facilities[,]. . . . HSE to implement fully aftercare guidelines[, and]. . . . HSE to monitor the effectiveness of discharge policies.”⁶

As regards prisoners and their follow-up care upon release, the plan identified as a priority, “Improv[ing] discharge planning for all individuals leaving prisons to include identification of housing needs and follow up supports, through close links between those discharging institutions and housing providers and community based services.”⁷ It recommended, amongst other things, that the “Irish Prison Service to put in place appropriate discharge procedures for homeless people from prisons.”⁸

It has also been noted that dissemination of information to primary health care providers for follow-up care upon patient discharge is particularly problematic when the patient is a member of the Traveller community. The Traveller Health Survey noted that “the data indicated that travelers found it difficult to articulate or explain themselves. Both men and women reported that they internalized communication breakdown as a personal problem associated with their inability to read, write, or understand the doctor or chemist. The narrative indicated that men felt a sense of shame or embarrassment.”⁹

² *Ibid.* at p. 34.

³ *Ibid.*

⁴ *Ibid.* at p. 63.

⁵ *Homeless Strategy Implementation Plan*, Dublin, Department of the Environment, Heritage and Local Government, at p. 10.

⁶ *Ibid.*

⁷ *Ibid.* at p. 11.

⁸ *Ibid.*

⁹ *All Ireland Traveller Health Study: Summary of Findings*, School of Public Health, Physiotherapy and Population Science, University College Dublin (2005) at p. 130.

1. International Standards

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which has been ratified by Ireland, is the primary human rights standard of relevance to the Data Set.

Article 12 of the ICESCR recognises the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and requires that individuals enjoy available, accessible, acceptable and quality healthcare (“the “AAQs”).¹⁰ The AAQs seek to address the social determinants of health and focus on guarding against discrimination and narrowing the gap in health outcomes between vulnerable or disadvantaged groups and the general population. The requirement of accessibility has four distinct elements: non-discrimination, physical accessibility, economic accessibility and information accessibility. The AAQs clearly require that the specific needs of minorities or those that are marginalised be taken into account.

Information accessibility, which is of direct relevance to the Data Set, is defined as including “*the right to seek, receive and impart information and ideas concerning health issues*”.¹¹ The Data Set is a positive measure by which health information is made accessible, and the following recommendations by the Commission are directed to ensuring that the rights comprehended within Article 12 of ICESCR are fully reflected in the Data Set.

2. The Application of the Data Set to Vulnerable and Disadvantaged Groups

a. Section 6.4—Clinical Narrative

The IHRC is concerned that several subsections in this section of the Data Set are optional (they may/may not be included in the standardised patient discharge summary information form), including: 6.4.1—Pertinent clinical information, 6.4.3—Operations and procedures, 6.4.8—Relevant investigations and results, 6.4.9—Relevant treatments and changes made in treatments, 6.4.10—Diet, 6.4.11—Functional state, and 6.4.12—Immunisations. The IHRC recommends that these subsections of the Data Set be required fields in order to better ensure that health information in relation to the discharged patient is fully transmitted to the patient themselves and those providing primary health care to them. Medical information is complex and difficult to understand for the majority of the population, and without a comprehensive report from a medical professional, there is a clear risk that patients themselves may not transmit their own medical information accurately. This risk is exacerbated if the person lacks literacy skills or where English is not their first language. In addition patients with mental health issues or those with an intellectual disability may have difficulty in communicating medical information effectively.

¹⁰ See Committee on Economic and Social Rights, General Comment 14, E/C.12/ 2000/4, at para. 12

¹¹ *Ibid*, at para 12.

Mandating that these subsections be required fields in the Data Set would better ensure that the most thorough information possible will be provided in discharge summaries and, as a result, that primary care healthcare professionals will be aware of any and all latent and ancillary concerns that should be taken into account when identifying and providing follow-up care for discharged patients. Further, thorough discharge summaries would function as a mechanism to insulate the Health Service Executive (HSE), physicians and other health care professionals from any possible negligence claims.¹²

The IHRC **recommends** that the aforementioned subsections should be required fields so as to provide an additional safeguard to ensure that the physician or other health care professional completing the discharge summary include any and all relevant information to the primary care healthcare professional. If a particular subsection is not relevant to a particular patient's treatment, it should be so indicated.

b. Section 6.6—Future Management

The IHRC is concerned that this entire section regarding future management, core to the area of follow-up care in the community, is optional. The IHRC recommends that this element should be a required feature of a discharge summary in light of the responsibility of the hospital to organise future actions on behalf of a patient, especially those that are vulnerable or disadvantaged and without means of organising such care for themselves. The care of a patient often continues after their discharge and the organisation of follow-up procedures and checks is a vital component of the right to health, especially for vulnerable patients.

This is particularly important with respect to section 6.6.4, which includes any advice or actions that were requested from other healthcare professionals. Without such information, it might be difficult for the discharged patient, particularly one that is vulnerable or disadvantaged, to be sure of what treatment is available to or recommended for him/her in the community. The absence of a clear direction in this field of the Data Set creates ambiguity for both the patient and primary health care workers as to whether further follow up is necessary.

¹² In *Reynolds v. UK*, [2012] ECHR 437, the European Court of Human Rights (ECHR), in finding that there was a breach of Article 13 (right to an effective remedy), found that there was an arguable claim that there had been a breach of the Article 2 (right to life) where a voluntary patient who was psychiatrically hospitalised but had been assessed as low-risk for suicide, has subsequently committed suicide by jumping out of a window in the facility. In *Rabone v. Pennine Care NHS Trust* [2012] UKSC 2, the UK Supreme Court has also found that the National Health Service had a positive duty under Article 2 to take reasonable steps to protect a young girl who committed suicide upon her discharge home from the real and immediate risk of suicide and failed in this duty.

c. Catchment Area

It does not appear that the patient discharge summary will include information on the relevant catchment area which a discharged patient falls within for follow-up community care. Nevertheless, Section 6.2.3 does require that an address be provided by the patient, which may prompt a health professional to indicate to the discharged patient what catchment area they fall within. However, catchment areas and public services are designed around the needs of people who live in conventional houses in community settings which naturally is reflective of how the majority of the population lives. The HSE provides its services within defined catchment areas and community care arrangements are generally made according to which catchment area one falls into. This is of no relevance where the person has no fixed abode, as services will often be difficult to access in a coherent manner, or it will be unclear as to where this person ought to present himself for care in the community.¹³ It does not appear that the Data Set anticipates that a discharged patient might be homeless, or possibly a member of the Traveller community with a nomadic way of life (although admittedly the numbers of such Travellers are now small) and while this is not a problem that arises from the Data Set itself, it is a difficulty that could usefully be addressed in the Data Set, such that anyone without a fixed address, is nonetheless assigned a catchment area, where they may avail of health care services on the same basis as other members of the community.

The Commission **recommends** that a mandatory field within the Data Set would be to identify the primary health care catchment area of the patient.

3. Concern that the Data Set does not include those discharged from all Institutional Settings or A&E Departments.

The Data Set relates only to patients being discharged from the acute care setting following admission to hospital, but appears not to envisage a discharge from A&E departments or institutional settings such as prisons and nursing homes and prisons. Section 5.1 of the Data Set specifically acknowledges this, and indicates that “limiting the scope” of the Data Set is a “more practical approach in the first instance”.

The IHRC questions the desirability of this approach and considers that the Data Set has applicability discharges from other settings.

With respect to prison discharges, in many cases prisoners may have their first consistent contact with medical care while in prison, and this link with medical

¹³ The Commission recently appeared before Dublin City Coroner, on behalf of the next of kin of a homeless man who died in March 2011. The man had been taken to the A&E Department of a major Dublin hospital after an apparent suicide attempt in the month before his death. It was apparent from the evidence tendered on behalf of the hospital that there was a perceived difficulty referring the man on for further psychiatric follow up in the community, as the man did not fall within a clear catchment area as he was homeless.

services is all too easily broken on the discharge of the prisoner.¹⁴ It is important that any prisoner that is under medical care while in prison is encouraged and able to access ongoing medical care in the community as necessary. The necessity to complete the Data Set for discharged prisoners under medical care would be a mechanism whereby the medical needs of the prisoner in the community are prepared for before they leave prison. At the present time the obligation on the Irish Prison Service to ensure the organisation of follow-up care in such circumstances is unclear. In light of the vulnerability of many of the prison population on release, there is a heightened obligation on health professionals to ensure adequate community care arrangements are made for those who are vulnerable and about to be released from prison.

While similar concerns may not arise when a person is leaving another institutional setting, nonetheless if the person has been under medical care in such a setting, it would seem appropriate that there is a smooth transition to community care, to which end the Data Set is an extremely important tool. Persons leaving other institutional settings might include older persons leaving nursing home care after a period of recuperation or a person with an intellectual disability moving from living in a congregated setting to living in the community. Continuity of care is of core importance to such persons, who may in one way or another have difficulty taking the initiative regarding their own health care.

The rationale for non-application of the Data Set to A&E Department discharges is of concern. While most visits to an A&E Department may be for one off treatment that will not arise again, many such visits will require follow up care, whether for further investigation or further medical treatment. In particular the Commission is mindful that A&E Departments often deal with persons having an acute psychiatric episode, and while they might not meet the criteria for psychiatric detention pursuant to the Mental Health Act 2001, may nonetheless need a clear plan for follow up care. It is unclear in this regard, where follow up care is clearly medically indicated, why the Data Set would not apply in such circumstances

The Commission **recommends** that the Data Set as appropriate include discharges from all institutional settings where persons may be under medical care, and A&E Departments.

4. Conclusion

The IHRC welcomes the draft National Data Set for Standardising Patient Discharge Information. In order to ensure the State's full compliance with the relevant international human rights instruments, the above recommendations have been made to strengthen the Data Set to ensure the utmost protection of the rights of discharged patients and the IHRC is hopeful that they will assist in the further development of these welcome standards.

¹⁴ For a detailed analysis of health care in Irish prisons see; *Guidance of Physical healthcare in a Prison Context*, Inspector of Prisons, 18 April 2011.

