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Potential of national/regional datasets to support targeted service planning

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Abstract

Aims

This survey reviewed the content of national and regional health datasets to assess their potential to support service planning and sub-population targeting.

Methods

The Health Information and Quality Authority catalogue (v.4) of health and social care datasets (129) was examined. Datasets relevant to the implementation of Sláintecare (37) were selected by consensus. A variable list was constructed for geographic granularity, and inclusivity measures. An online survey of the presence of parameters was sent to the database managers in Microsoft Forms. Analysis was descriptive.

Results

The survey response rate was 33/36 (92%), (one duplicate removed). Age was recorded on all databases and sex on 31/33 (94%). Socio-economic, medical-card and education status were poorly recorded on 11 (33%,) 10 (30%) and 9 (27%) databases respectively). Race, ethnicity or cultural details were recorded on 16 (49% and disability on 12 (36%). County was recorded on 27 (82%) , Health Region (not current) on 13, (38%) electoral division on 11 (33%), and CSO small area on 8 (24%). Concerns around GDPR and lack of resources emerged as key themes from comments.

Discussion

Existing datasets have large gaps in variables that could support tailored health service planning. A standardised approach to the inclusion of critical parameters within health datasets is required to support the full implementation of Sláintecare.

Background

A key aim of the Health Reforms under Sláintecare[1] is to conduct population-based planning based on needs assessment and to support Population Health Management (PHM), with a specific focus on vulnerable groups. Implementation of Population-based Resource Allocation (PBRA) in the new Health Regions[2] demands a health equity focus. Recent evidence shows that despite an overall improvement nationally in deprivation measures, the gap between Ireland's most disadvantaged areas and the national average has increased[3]. This makes equity based planning and tailored service delivery an imperative.

The aim was to review the variables currently present in national and regional health datasets to assess their potential to support targeted service planning and delivery of tailored interventions for sub-populations at all geographical levels e.g. national, regional and local neighbourhoods. The specific objectives were to determine the degree to which indicators of inclusivity and geographical granularity are present and to recommend how the potential of health-related datasets might be enhanced.

Methods

The Health Information and Quality Authority (HIQA) catalogue v 4.0 of health and social care datasets was examined (129 datasets)[4]. The catalogue groups data collections according to six categories: national and regional data collections, censuses, national surveys, national performance reports and additional sources of health information. A list of publicly available datasets based on these was extracted. Inclusivity identifiers were informed by the findings of recent review of inclusion of equity stratifiers using the PROGRESS Plus framework (Place of residence, Race (or ethnicity), Occupation, Gender (or sex), Religion, Education and Socioeconomic status (SES) and Social capital) for the measurement of health inequalities within HIQA Catalogue, version 3.0[5].

Additional inclusivity indicators were retrieved from Census 2022 e.g., birthplace, nationality (citizenship), language spoken at home (other than Irish/English).. Eligibility for General Medical Services (GMS) status was also included. Geographical (personal and healthcare) indicators such as place of residence, address, Eircode, geographical co-ordinates, Central Statistics Office (CSO) small areas, electoral divisions, county, local authority, local health office, primary care team, community health network and health region were identified. A final list of datasets useful for national and regional service planning was agreed by consensus. An online survey of the presence of these parameters, and factors affecting recording of inclusivity identifiers and granular geography, was sent to the database managers (37) using Microsoft Forms. Analysis was descriptive. Open comments were grouped into themes.

Results

Two regional registers recorded identical data and were counted as one. Of the 36 datasets selected as being appropriate for national and regional planning, 28 were national data collections including eight audits by the National Office of Clinical Audits (NOCA), two regional data collections and six national surveys (3 cohort and 3 cross-sectional). Of the 129 datasets in the online HIQA catalogue, only 10 (7.8%) were accessible via an open access portal or a mechanism was available for the provision of data on request".

The survey response rate was 92% (33/36). Results are shown in the Table. Inclusivity indicators other than age and sex were recorded in a minority of datasets. Completion rates of >60% were reported for County, place of residence and address.

Themes from open comments

Two key themes emerged, concerns around GDPR and lack of resources:

"DED (District Electoral Division) (*data were*) collected from 1996 - 2015. On recommendation of EU Joint Research, in light of GDPR, this was reduced to Local Authority level from 2016".

"Inclusivity and Place of Residence Indicators are limited due to GDPR and privacy issues".

"Eircodes and Health Regions are intended to form a part of the database in the future but have not been incorporated as of this date".

Table: Inclusivity and geographical indicators to support population-based planning

Inclusivity Indicators			**Geographical Indicators**		
	N	**%**		***N***	**%**
Age	33	100.0	County	27	81.8
Sex	31	93.9	Place of Residence	26	78.8
Race/Ethnicity/Cultural Background	16	48.5	Address	20	60.6
Occupation	14	42.4	Eircode	16	48.5.
Education	9	27.3			
Country of Birth	13	39.4	Health Region	13	38.2
Disability	12	36.4	Electoral Division	11	33.3
Marital Status	12	36.4	CSO Small Area	8	24.2.
Socio-Economic Status	11	33.3	Geographical co-ordinates	3	9.1
GMS	10	30.3	Local Health Office	7	21.2
Nationality	6	18.2	Local Authority	3	9.1
Sexual Orientation	6	18.2	Primary Care Team	3	9.1
Language other than Irish/English	5	15.2	Community Health Network	3	9.1
Religion	4	12.1			

Discussion and Conclusion

Our survey showed that existing national and regional datasets have large gaps in variables that could support equity-based service planning. The PBRA model, to be implemented in 2024, adjusts Regional Health Authority populations by Age-Sex, Deprivation and Rurality. Currently around one-third of datasets complete SES. Completion rates for Electoral Division (ED) and Small Area (SA) combined are <60%. Concerns around GDPR compliance appear to be reducing collection of useful information.

The forthcoming Health Information Bill aims to implement the legislative framework for the collection, use, reuse and sharing of health information using a unique health identifier to support data-driven health service delivery, research and PHM[6]. It addresses the need to strike a balance between data protection and data sharing. According to HIQA, the Bill provides an opportunity to prioritise comprehensive national data collection to inform planning and management of services and to establish a legal requirement for this[7]. Greater public and professional engagement is needed to build trust with appropriate safeguards and governance structures[7]. This is partly being driven by the European health data space, which proposes legislation focusing on the re-use of data and data sharing across sectors in Europe[8]. Our findings show that that key national data collections have major gaps in inclusivity and geographical measures. We recommend that these be restructured to comprehensively include indicators to support planning for health equity.

Declaration of Conflicts of Interest:

None declared.

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