

CASE STUDY ON INFCAREHIV

Context

InfCareHIV is the national quality registry that is actively monitoring HIV in Sweden. Caring for PLHIV is complex and requires a multi-disciplinary approach. InfCareHIV addresses this, offering a decision-support tool, quality assurance, educational resources, opportunities for consultation and a research database.

Introduction

InfCareHIV has been used at the Karolinska University Hospital since 2003 and at all 29 Swedish HIV-clinics since 2008. Its steering group is diverse, made up of leading clinicians, nurses, academics and administrators as well as observer members from patient groups. In 2016, Sweden became the first country in the world to reach the UNAIDS/WHO 90-90-90 target. InfCareHIV played an important role here by ensuring people were linked to and retained in care. Initially, InfCareHIV found major discrepancies in care quality and outcomes across clinics in Sweden. By presenting national comparisons annually, those clinics delivering sub-par results were pressed to improve their performance. Over time, the major discrepancies across Sweden were levelled out, delivering more evenly-balanced, higher-quality care for people living with HIV (PLHIV) – vital for meeting the 90-90-90 target.

Aims

The overarching goal of the quality registry is to improve and make care for PLHIV more consistent across Sweden by identifying those individuals and groups within the patient population that are experiencing poorer treatment outcomes and reallocating existing resources to improve this situation.

Method

InfCareHIV's platform has four main components: decision support, quality assurance, consultation and research. At the core of all of these lies individual patient data, entered on a daily basis by healthcare professionals. Much of the laboratory analysis is transferred electronically directly to the platform. Patients can also complete an annual electronic questionnaire on their quality of life via a computer or handheld device. By bundling these inputs, the quality of data increases; several external analysis (e.g. by IBM Haifa) have confirmed that InfCareHIV has an exceptionally high quality of input data. Clinics and patients can, at any given time, monitor development and progress towards agreed goals. Should clinics require advice or a second opinion on a particular patient case, they can use the InfCareHIV platform to have a quick and efficient consultation from leading clinicians. A comparison of all Swedish clinics is presented annually and is evaluated both nationally and internationally.

Results

The data suggests that >99% of patients are linked to and retained in care, 98% receive antiretroviral therapy (ART) and 96% have undetectable plasma viremia following >6 months of treatment. The InfCareHIV system provides an efficient way of educating patients, of whom a substantial number provide information on their quality of life through the electronic questionnaire. This survey, which has been conducted for the last six years, sees patients offering insights on aspects such as their physical, mental and sexual health as well as providing their perceptions on the quality of care received. Results suggest that quality of life is improving for PLHIV and that engagement is increasing – today, 35% of all PLHIV now respond to the survey.

The survey allows health care professionals to improve follow up on those patients that are experiencing a poorer quality of life using a more personalised approach. However, a clinical issue is that long-term comorbidities are not fully captured in InfCareHIV. As PLHIV continue to age, it raises further questions and concerns. InfCareHIV is working to establish direct, automatic transfer of biomarkers from hospital eHealth systems to the platform's decision support tool. InfCareHIV's comorbidity module can also connect to, for example, the Swedish Board of Health and Welfare comorbidity register and the national prescribed drug register. In addition, the InfCareHIV database is frequently used for research and to improve HIV care in Sweden.

Recommendations

Clinical care and research in Sweden can be further improved by expanded use of the InfCareHIV platform through transfer of biomarkers and connection to other key Swedish registries. The platform brings together clinical and laboratory data for patient level research. Important parameters, gained from routine healthcare R&D work, enable professionals to initiate research on priority areas such as comorbidities and PLHIV that are ageing. Greater emphasis on expanding aspects such as quality of life, as well as defining a fourth 90 for quality of life assessment, is a priority.

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