ORIGINAL ARTICLE

Alliance for the development of the Argentinian Hip Fracture Registry

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Abstract

Summary Age expectancy has significantly increased over the last 50 years, as well as some age-related health conditions such as hip fractures. The development of hip fracture registries has shown enhanced patient outcomes through quality improvement strategies. The development of the Argentinian Hip Fracture Registry is going in the same direction.

Introduction Age expectancy has increased worldwide in the last 50 years, with the population over 64 growing from 4.9 to 9.1%. As fractures are an important problem in this age group, specific approaches such as hip fracture registries (HFR) are needed. Our aim is to communicate the Argentinian HFR (AHFR) development resulting from an alliance between Fundación Trauma, Fundación Navarro Viola, and the Argentinian Network of Hip Fracture in the elderly.

Methods Between October 2020 and May 2021, an iterative consensus process involving 5 specialty-focused meetings and 8 general meetings with more than 20 specialists was conducted. This process comprised inclusion criteria definitions, dataset proposals, website deployment with data protection and user validation, the definition of hospital-adjusted registry levels, implementation planning, and sustainability strategies.

Results By June 2021, we were able to (1) outline data fields, including epidemiological, clinical, and functional dimensions for the pre-admission, hospitalization, discharge, and follow-up stages; (2) define three levels: basic (53 fields), intermediate (85), and advanced (99); (3) identify 21 benchmarking indicators; and (4) make a correlation scheme among fracture classifications. Simultaneously, we launched a fundraising campaign to implement the AHFR in 30 centers, having completed 18.

Conclusion AHFR development was based on four pillars: (1) representativeness and support, (2) solid definitions from onset, (3) committed teams, and (4) stable funding. This tool may contribute to the design of evidence-based health policies to improve patient outcomes, and we hope this experience will help other LMICs to develop their own tailored-to-their-needs registries.

Keywords Hip fractures · Registry · Aged · Quality improvement · Frailty · Osteoporosis

Introduction

One of the most outstanding aspects in the last 100 years has been the increase in life expectancy, which was, on average, 34 years in 1913, and over 70 years nowadays [1]. Due to this, the ratio of people over 64 years old in the world population has doubled from 4.9 to 9.1% in the last 50 years [2]. This is one of the reasons why a deep analysis of the many ways of living adulthood is needed. Aligned with this, the World Health Organization (WHO) proposed the 2020–2030 period as the Decade of Healthy Aging. This initiative is set under the framework of the widespread acceptance of the agenda to meet the Sustainable Development Goals (SDG). It proposes that every person should accomplish their potential in equity and dignity in a healthy environment [3]. It also presents the initiative as "global collaboration, aligned with the last ten years of the Sustainable Development Goals, that brings together governments, civil society, international agencies, professionals, academia, the media, and the private

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sector to improve the lives of older people, their families, and the communities in which they live" [4].

According to this, it is essential to consider all the events that increase the gap between the aging process and a state of complete health, being hip fracture one of the most important ones. Given the high impact this problem has on elderly people, such as social vulnerability, project-of-life restrictions, isolation, loss of autonomy, and emotional distress, there is a clear need for a socio-sanitary and multidisciplinary approach [5].

As mentioned, hip fracture is one of the most important problems the elderly face, affecting approximately 1.6 million people per year worldwide, with a projection of 6.3 million for 2050 [6, 7]. In Latin America, a rise in hip fractures has been noted, but the accuracy of the information is generally poor [8, 9]. Argentina is not the exception, with some approximations extracted from published research estimating an incidence in women of 252 fractures/100,000 inhabitants/year (range 144 to 405) and men from 78 to 181 [10].

Disease-specific registries allow for articulating actions of different actors toward better results for patients. These tools collect bedside data at public and private hospitals and transform them into pertinent and timely information to be used by idoneous healthcare agents. The high morbidity and mortality rates associated [11–15] with hip fractures set a point for the need to monitor patient outcomes, complications, and adverse events. Patient-based registries are a key tool for these purposes. Many countries have addressed this aspect by developing national hip fracture registries (HFR) (Sweden, UK, Spain, Australia and New Zealand, Scotland, and Ireland) while others are still under development (USA) [16]. These national HFRs have been a key element for the monitoring of clinical and surgical practices, identifying gaps between real and expected results, and having the sensibility to measure the consequences of corrective actions. Moreover, the use of HFRs has been linked to robust outcomes improvement, such as mortality rate decrease, when implemented in association with quality improvement programs (QIP) [17–19], and these registries have been used as a cornerstone for the implementation of other interventions, such as fracture liaison services [20].

Despite the aforementioned benefits reported in high-income countries (HIC), HFR are scarcely replicated in low and middle-income (LMIC) ones. The challenge for the implementation of such interventions in LMICs is bigger, as the deployment of electronic health records (EHR) is still in its early phases [21, 22]. Thus, data cannot interoperate between EHR and HFR and must be uploaded manually. In 2019, Fundación Trauma (FT) set a collaborative agreement with Fundación Navarro Viola (FNV) and the Argentinian Network of Hip Fracture in the Elderly (RAFCA, for its Spanish acronym) to develop the first national HFR. The objective of this manuscript is to communicate the experience of the development of the Argentinian Hip Fracture Registry (AHFR), hoping that it could help other LMICs to develop their own tailored-to-their-needs registries.

Methods

Background: Argentinian healthcare system

Argentina's healthcare system is composed of three sectors with uncoordinated actions: public, social security, and private. The public sector is funded by taxes and retentions that finance national, provincial, and municipal facilities. Social security finances its healthcare benefits via the retention of employers' contributions and part of the registered workers' salaries. The private sector, which is composed of prepaid health insurance, is financed by direct payment from their beneficiaries. While the countrywide coverage is a fact, there are huge differences in the benefits, mainly related to the variation in the beneficiaries/resources ratio each sub-system has. This situation exposes the system to a high degree of inequality and inequity. Even though a plan toward universal coverage was initiated 5 years ago, it has not yet reached its goal of defining a homogeneous set of rules that could facilitate better resource assignment, boosting the quality of care and equity in access [23]. The current aforementioned fragmentation precludes the system from providing adequate quality of care.

Experience

RAFCA is a non-profit NGO composed of 11 scientific societies created in August 2019 with the aim of establishing the best clinical practices for the care of patients affected by hip fractures and other fragility fractures. It is now composed of Academia Nacional de Medicina (ANM), Asociación Argentina de Ortopedia y Traumatología (AAOT), Asociación Argentina de Osteología y Metabolismo Mineral (AAOMM), Asociación Argentina de Salud Pública (AASAP), Sociedad Argentina de Geriatría y Gerontología (SAGG), Sociedad Argentina de Medicina (SAM), Sociedad Argentina de Medicina Física y Rehabilitación (SAMFyR), Sociedad Argentina de Medicina Interna General (SAMIG), Sociedad Argentina de Osteoporosis (SAO), Sociedad Argentina de Reumatología (SAR), and Fundación de Investigaciones Metabólicas (FIM).

FT, a non-profit NGO that has been running a trauma registry in 15 hospitals since 2010, presented the results of the analysis of a subsample of elder patients with hip fractures at a local Geriatrics Congress in 2019. At that moment, the Argentinian Association of Orthopedics & Traumatology—a member of RAFCA—was carrying out a survey-based research project that was published after reaching 1000

responses [24]. RAFCA found in FT's experience the ideal partner for the development of an Argentinian HFR. This partnership was not complete until FNV, a non-profit NGO that works to promote comprehensive development in the first childhood and to transform the reality of the elderly, became part of it. The results of the analysis of the small sub-sample included in FT's registry, at that moment with a size of 823 subjects, helped in the initial characterization of hip fractures in Argentina. This process of building an alliance between an organization devoted to developing data-driven quality improvement programs in trauma and an organization that works toward the improvement of hip fracture care has also been recently described in the USA between the American College of Surgeons and the American Academy of Orthopedic Surgeons [16].

Initial activities

The initial stage lasted between September 2019 and March 2020 and involved the definition of the participating organizations, the signing of agreements between the parts, and definitions of funding. RAFCA appointed a representative for operational tasks, FNV committed itself to providing funds for the development of the AHFR and its implementation during the first year, and FT contributed with its experience in the development and implementation of the aforementioned hospital-based trauma registry.

Alliance goals

The main goals of this project are (1) to characterize the process of patient care during the acute phase, both while hospitalized and after hospital discharge, and (2) to measure the impact of hip fractures in Argentina and to identify the bio-psycho-social needs of the affected persons. These actions are directed toward the identification of opportunities for quality improvement (QI), promoting early rehabilitation, designing data-driven prevention strategies, stimulating an early recovery and social reintegration, performing benchmarking evaluations between hospitals and international registries, and promoting network activities with scientific societies, universities, NGOs, government offices, and patient associations. One of the ways these objectives can be met is by publishing annual reports on key data points, such as distribution of fracture types and groups, ongoing preventive treatment, time from admission to surgery, reasons for surgery delay, in-hospital complications, hospital length of stay, and discharge destination. As hospitals will enter the AHFR in a gradual manner and the sample for the first period is assumed to be small, the Alliance agreed to publish—at least initially—global data with no identification of each center. The objective is to publish the first report no later than the second year after the incorporation of the first center, as long as the sample of hospitals is over five. These are dynamic definitions that will be updated during the monthly meetings of the working group.

Target population

The inclusion criteria of the AHFR will be patients 60 or more years of age [25] that present fractures of the femoral neck, intertrochanteric region, or subtrochanteric region. These fractures comprise nearly all operative, low-energy, fragility-type fractures in the elderly population and are represented in S72.0, S72.1, and S72.3 codes from the Tenth International Classification of Diseases.

Process for variable selection

A team composed of a representative of RAFCA and four members of FT performed a web search for similar experiences, either with a traditional approach, via PubMed and LILACS with this strategy: ("Hip Fractures"[Mesh]) AND "Registries"[Mesh], or informal searches in annual reports from established national registries, and recommendations of data sets from organizations like the Fragility Fracture Network and the International Osteoporosis Foundation. This search was later complemented with direct communications with HFR developers when needed.

Between October 2020 and May 2021, an iterative consensus process that involved five specialty-focused meetings and eight general meetings with more than 20 specialists was conducted. This process comprised inclusion criteria definitions, dataset proposals, development of an exclusive online site with data security and user validation, the definition of registry levels according to the heterogeneity of healthcare in Argentina, and definitions of the implementation plan and the sustainability strategy.

Legal aspects

The design of the AHFR was conducted following the statements of the Argentine Law on the protection of personal data (25,326), which was considered "adequate" by the European Union [26]. This law expresses three key aspects regarding the construction of health-related information systems, databases, or records: (1) "Consent [of the person for the use of their data] is not required when (…) it is personal data related to health, and it is necessary for reasons of public health, emergency or to conduct epidemiological studies, as long as the identity of the subjects is preserved through adequate dissociation mechanisms," (2) "Consent is not required (…) if an information dissociation procedure has been applied so that the owners of the data are unidentifiable," and (3) "Public or private health facilities and professionals linked to the health sciences can collect and treat

the personal data related to the physical or mental health of the patients who are or have been treated by them, respecting the principles of professional secrecy." Since AHFR collects personally identifiable data but encrypts it and dissociates it from health data, it complies with the law. According to this, personally identifiable data can be consulted by the hospital healthcare team where the patient is assisted, but not by users outside the organization.

Results

By June 2021, we were able to (1) outline the package of 99 fields that include epidemiological, clinical, and functional dimensions for the pre-admission, hospitalization, discharge, and follow-up stages; (2) define three registry levels: basic (53 fields), intermediate (85 fields), and advanced (99 fields); (3) identify 21 indicators for performance evaluation and benchmarking, and (4) make a correlation scheme between the most used hip fracture classifications. Simultaneously, we launched a fundraising campaign to implement the AHFR in 30 centers, having so far reached the funds for 18. The whole process is outlined in Fig. 1.

Classification

Some special meetings were held with small groups to discuss the definition of the types of fractures that would be included. Three meetings were held with a group of leading orthopedic surgeons in this type of injury to define the classification that the AHFR would use. The controversial points were (1) the AHFR should use the AO/OTA classification in order to dialog with HFRs from the rest of the world; (2) in Argentina, there is a significant number of orthopedic surgeons who continue to use classifications such as Garden and Pauwells. The way to solve this problem was to develop a correlation between the different classifications and incorporate it dynamically into the registry, in order to meet both objectives. This correlation was developed by the orthopedic surgeons that are part of the RAFCA.

In relation to atypical fractures, two meetings were held with the group of endocrinologists and metabolism specialists, reaching the conclusion of incorporating ASBMR Task Force criteria from 2013 in the registry for those cases of subtrochanteric fractures [27].

Data collection procedures

A key aspect related to the disparity in the implementation of health information systems in Argentina was the definition of the methods to collect the data and its input in the registry. Given that most of the Argentine public hospitals still have paper-based clinical records, the path of automatic electronic input from other sources, such as electronic health records (EHR), could not be the only option. In this sense, the input of data in the hip fracture database had to include a graphical interface so that the teams at each hospital could load the data primarily, right from their paper-based clinical records. However, to avoid double processes in public or private hospitals that have developed information systems, a REST API (application programming interface according to the restrictions of the
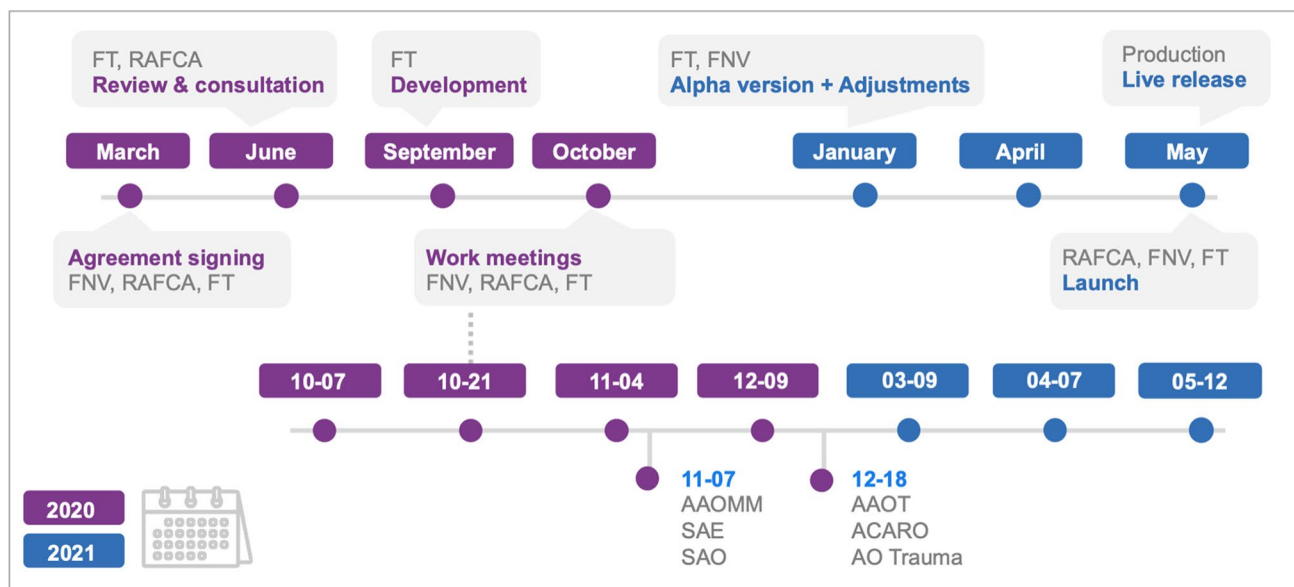

Fig. 1 Outline of the AHFR development

REST architecture, i.e., representational state transfer) was developed to facilitate the input of information from EHRs. The process included the definition of the document that would function as the message, the development of the interface to capture those messages, and the specifications for the hospitals' IT (information technology) teams to develop the document. The complete process includes the validation of the document by the application at the time it is uploaded and an automatic reply to the user in terms of acceptance and inclusion or rejection in the database and a follow-up report of the reasons for the latter.

Regardless of whether the input of data is carried out one way or another, it was defined that hospitals should have a part-time dedicated team to monitor and load data since the automatic migration of all the AHFR fields is not feasible in practice. This team will be made up of an institutional representative (usually someone from the Board of Directors), the program manager (a physician or nurse dedicated to the care of patients with hip fractures), and a registrar (a person with an administrative background), who will be the ultimate responsible person for the quality of uploaded data. According to the volume of data the hospital handles, one or more registrars will be defined as needed.

Variable selection

The first version of the dataset was composed of 66 fields for the full version, 59 for the intermediate, and 36 for the basic level. The iterative process led to the expansion of the initial proposal that, in its final version, is composed of 99, 85, and 53, respectively (Table 1). One of the aspects that led to more room for discussion was the definition of the expected lapse from admission to surgery, which according to international criteria may be set at 48 or 72 h. In Argentina, there is no reference standard for this aspect, which is why the team decided to leave this field as an open variable, recording (1) date and time of hospital admission, (2) date and time of the start of surgery, (3) evaluation of whether there was a delay in surgery performance according to the team, and, if so, (4) the reason why it occurred.

Key performance indicators

The process for the selection of indicators followed a similar path to the rest of the definitions, beginning with a web search, which was then submitted for evaluation by the working group. The final list was made up of 11 indicators for the basic level, 16 for the intermediate, and 21 for the advanced (Table 2).

Discussion

Throughout the first year of collaborative work, the Alliance was able to (1) define the optimal, locally developed, and internationally adjusted dataset; (2) fund the initial step of the process; and (3) begin the meetings with interested hospitals.

We believe this was possible due to the commitment of a multidisciplinary and active working group and a vision toward the integration with other hip fracture–related programs such as fracture liaison services.

This process was similar to that of other established registries, like the ones from the UK [28], Spain [29], and Mexico [30], where multidisciplinary working groups led the initial research activities that ended up as national registries. A distinctive aspect of this project is the joint between physicians from hip fracture–related specialties and two NGOs with experience in fundraising, and in technical aspects of the collection and analysis of health and healthcare-related data, respectively.

The launch of national HFRs was associated not only with survival rate improvement, as shown by the British initiative [31], but also with the optimization of other quality indicators [32]. This improvement in survival was, at least partially, related to the reduction in the admission-to-surgery time window, as was also revealed by registries from other regions, like Ontario [33] and Denmark [34]. These findings led to the currently recommended 36- [35] or 48-h [36] thresholds. When discussing the most appropriate threshold for the AHFR, the group decided to leave it open (considering the aforementioned diversity in the country's access to care), at least during the first year of data collection. The group consensus idea supporting the decision to leave this criterion open was related to the hypothesis that equivalent results may be seen with different timing of surgery. Therefore, setting an arbitrarily fixed time to consider a delay may expose hospitals to an extremely high standard so that a substantial number of them would "fly under the radar" [37]. This remains a critical issue to monitor closely so that we can hopefully find a local national standard to define surgery delay.

Having contextualized the development up to this point, we believe that some opportunities for the project at this time are (1) the absence of similar projects in the region, (2) the potential for improving patient's experience while being treated, and (3) the integration of healthcare and management teams in hospitals. Yet, some threats remain: (1) lack of commitment of the institutions for the implementation of quality improvement programs, (2) potential competition with other information systems, (3) difficulties in achieving dedicated local teams in hospitals, and (4) the challenge to escalating the strategy to a national level.

Table 1 AHFR data fields

#	Section and fields	Basic	Intermediate	Advanced
A	Case identification			
1	Age check (>=60)	✔	✔	✔
2	Hospital code	✔	✔	✔
3	Case code	✔	✔	✔
B	Patient			
4	Clinical record code	✔	✔	✔
5	ID type	✔	✔	✔
6	ID number	✔	✔	✔
7	First name	✔	✔	✔
8	Other names	✔	✔	✔
9	First surname	✔	✔	✔
10	Other surnames	✔	✔	✔
11	Birthdate or age (in years)	✔	✔	✔
12	Sex (legal gender)	✔	✔	✔
13	Gender	✔	✔	✔
14	Address	✔	✔	✔
15	ZIP code	✔	✔	✔
16	Telephone 1	✔	✔	✔
17	Telephone 2	✔	✔	✔
18	E-mail	✔	✔	✔
19	Place of residence and level of support	✔	✔	✔
20	Medical insurance	✔	✔	✔
21	Type of medical insurance	✔	✔	✔
C	Admission and medical history			
22	Date and time of admission	✔	✔	✔
23	Transferred from other facility	x	✔	✔
24	Time spent on the previous facility	x	✔	✔
25	Hospital sector of first assistance	✔	✔	✔
26	Weight	✔	✔	✔
27	Height	✔	✔	✔
28	Cognitive evaluation (Pfeiffer)	x	✔	✔
29	Functional status (Katz)	x	x	✔
30	Comorbidities (Charlson)	x	✔	✔
31	Nutritional risk assessment (MNA)	x	✔	✔
32	Fragility state (CFS)	x	✔	✔
33	Pain assessment	✔	✔	✔
34	Pain assessment modality	✔	✔	✔
35	Pain management (drugs)	✔	✔	✔
36	Falls in the previous year	✔	✔	✔
37	Previous fractures	✔	✔	✔
38	Time of the previous fracture	x	x	✔
39	Localization of the previous fracture	x	✔	✔
40	Osteoporosis-related treatment (drugs)	x	x	✔
41	Length of osteoporosis related-treatment	x	x	✔
42	Withdrawal of osteoporosis-related treatment	x	x	✔
43	Risk factors assessment	x	x	✔
44	Pre-fracture gait status (NMS)	x	✔	✔
D	Fracture			
45	Date of fracture	✔	✔	✔
46	Place of fracture	✔	✔	✔

Table 1 (continued)

#	Section and fields	Basic	Intermediate	Advanced
47	Injury mechanism	✓	✓	✓
48	Laterality of affected hip	✓	✓	✓
49	Fracture type	✓	✓	✓
50	Fracture group	✓	✓	✓
51	Fracture subgroup	✓	✓	✓
52	Periprosthetic fracture	✓	✓	✓
53	Atypical fracture criteria	x	✓	✓
E	Procedures			
54	Evaluation by medical specialties (internal medicine, geriatrics, orthopedics)	x	✓	✓
55	Date and time of the evaluation by specialties	x	✓	✓
56	Deep venous thrombosis prophylaxis	✓	✓	✓
57	Physical status classification (ASA)	x	✓	✓
58	Surgical procedure	✓	✓	✓
59	Date and time of surgical intervention	✓	✓	✓
60	Delay in surgical intervention	✓	✓	✓
61	Cause of the delay in surgical intervention	✓	✓	✓
62	Type of surgical procedure	✓	✓	✓
63	Prosthetic material place or origin	x	x	✓
64	Anesthesia type	x	x	✓
65	Urinary catheter placement	x	✓	✓
66	Date and time of urinary catheter removal	x	✓	✓
67	Early mobilization	✓	✓	✓
68	Complications	✓	✓	✓
69	Surgical reintervention previous to hospital discharge	x	✓	✓
70	Type of surgical reintervention previous to hospital discharge	x	x	✓
71	Delirium assessment within the first week of surgery	x	x	✓
F	Hospital stay			
72	Intensive care unit admission	✓	✓	✓
73	Intensive care unit stay	x	✓	✓
74	Hospital ward in which the patient spent the most time of their stay	✓	✓	✓
G	Discharge			
75	Cognitive evaluation (Pfeiffer)	✓	✓	✓
76	Falls risk assessment (Downton)	✓	✓	✓
77	Prescribed treatment for fracture prevention	x	✓	✓
78	Transfer	x	✓	✓
79	Date and time of discharge	✓	✓	✓
80	Discharge condition	✓	✓	✓
81	Discharge destination	✓	✓	✓
H	Post-hospital follow-up			
82	Date and time of first contact (30 days post-discharge)	x	✓	✓
83	Vital condition at 30 days post-discharge	x	✓	✓
84	Place of residence at 30 days post-discharge	x	✓	✓
85	Readmission at 30 days post-discharge	x	✓	✓
86	Cause/s of readmission at 30 days post-discharge	x	✓	✓
87	Surgical reintervention within 30 days post-discharge	x	✓	✓
88	Types of surgical reintervention within 30 days post-discharge	x	✓	✓
89	Treatment for secondary prophylaxis at 30 days post-discharge	x	✓	✓
90	Mobility assessment at 30 days post-discharge (CAS-E)	x	x	✓
91	Functional status at 30 days post-discharge (Katz)	x	x	✓
92	Gait status at 30 days post-discharge (NMS)	x	✓	✓

Table 1 (continued)

#	Section and fields	Basic	Intermediate	Advanced
93	Date and time of first contact (120 days post-discharge)	x	✔	✔
94	Vital condition at 120 days post-discharge	x	✔	✔
95	Place of residence at 120 days post-discharge	x	✔	✔
96	Treatment for secondary prophylaxis at 120 days post-discharge	x	✔	✔
97	Mobility assessment at 120 days post-discharge (CAS-E)	x	x	✔
98	Functional status at 120 days post-discharge (Katz)	x	x	✔
99	Gait status at 120 days post-discharge (NMS)	x	✔	✔

Table 2 AHFR performance indicators

#	Indicator	Basic	Intermediate	Advanced
1	Global data completeness	✔	✔	✔
2	Gender identity recorded	✔	✔	✔
3	Age at admission recorded	✔	✔	✔
4	Documentation of pain assessment at admission	✔	✔	✔
5	Report of time spent from admission to surgery	✔	✔	✔
6	Early mobilization recorded	✔	✔	✔
7	Medical specialities evaluation registered	✔	✔	✔
8	Pressure ulcers evaluated and recorded	✔	✔	✔
9	Falls risk assessment (Downton) performed and recorded	✔	✔	✔
10	Destination at discharge recorded	✔	✔	✔
11	Fatality rate at hospital discharge	✔	✔	✔
12	Documented ASA evaluation	x	✔	✔
13	Documented cognitive evaluation	x	✔	✔
14	Documentation of patient-unrelated reasons for the delay in surgical intervention	x	✔	✔
15	Prescribed and documented secondary prophylaxis medication	x	✔	✔
16	Prescribed and documented thromboprophylaxis	x	✔	✔
17	Rate of patients effectively contacted at 30 days post-discharge	x	x	✔
18	Rate of patients with surgical reintervention within 30 days post-discharge	x	x	✔
19	Fatality rate within 30 days post-discharge	x	x	✔
20	Rate of sustained secondary prophylaxis medication at 30 days post-discharge	x	x	✔
21	Rate of patients with functional dependency at 30 days post-discharge	x	x	✔

Conclusion

The development of the AHFR was based on 4 pillars: (1) representativeness and support, (2) solid definitions from the start, (3) committed teams, and (4) stable funding. This was the result of the collaborative work between the three stakeholders. We believe this tool will contribute to the designing of evidence-based public policies to reduce morbidity and mortality of hip fracture patients, improve people's quality of life, and promote healthy aging.

The AHFR is a pioneering experience in the region, planned in a context of public–private articulation, including civil organizations. Moreover, it is proposed as a milestone for the implementation of follow-up strategies for patients with hip fractures through models that have been successful and cost-effective in other regions, such as fracture liaison services.

Declarations

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