ASIA PACIFIC FRAGILITY FRACTURE ALLIANCE (APFFA)
c/o Asia Pacific Orthopaedic Association
Unit 1.6, Level 1, Enterprise 3B, Technology Park Malaysia (TPM)
Jalan Innovasi 1, Lebuhraya Puchong - Sungei Besi
Bukit Jalil 57000,
Kuala Lumpur, Wilayah Persekutuan
MALAYSIA
secretariat@apfracturealliance.org.au

Backgrounder **EMBARGOED: 12:01AM AEST, TUESDAY, JUNE 15, 2021**

The Hip Fracture Registry Toolbox

About the Hip Fracture Registry Toolbox

- Developed by the Asia Pacific Fragility Fracture Alliance Hip Fracture Registry Working Group, APFFA HFRWG, in collaboration with the Fragility Fracture Network (FFN) Hip Fracture Audit Special Interest Group, the **Hip Fracture Registry Toolbox is a world first, informative and practical resource that extracts key findings from existing national and regional hip fracture registries, to advocate for, and support clinicians, hospital administrators, healthcare systems and governments with establishing a national registry within their respective countries.**
- The Toolbox:
    - explains the fundamental need for hip fracture registries;
    - features a practical guide on the various components involved in establishing a registry;
    - offers direction on stakeholder engagement and consolidation, advocating for change, planning and funding a registry, setting up a pilot registry, and navigating governance and ethics approval; and
    - includes established registry case studies and other useful resources.

Purpose of a hip fracture registry

- Registries for any health condition provide a mechanism to identify and investigate variations in the provision of patient care.
- While basic registries can determine where variations exist, the more robust registries can examine the drivers behind these variations.
- Given the exponential increase in both the incidence and costs associated with hip fractures to date, and those anticipated globally,[1] hip fracture registries act as an essential tool for clinicians, hospital administrators, healthcare systems and governments in the Asia Pacific region, and through the world, to underpin quality improvement initiatives.[2]
- Widescale implementation of hip fracture registries globally can facilitate vast improvements in care for the millions of people who sustain a hip fracture each year.[3,4]
- Hospitals can utilise hip fracture registries to benchmark their provision of care against best practice clinical standards for acute care, rehabilitation, and secondary fracture prevention.[2,3]
- Furthermore, hip fracture registries transform patient-level data into information that can equip and empower hospital teams to identify the key challenges to overcome within their respective institutions, develop solutions to these challenges, and therefore strive for ongoing improvement in care.[2]

- As of April 2021, 18 countries across Asia Pacific, Europe, Latin America and North America had established a hip fracture registry, at different stages of maturation, participation and development.[5-21]
- With adequate operational efficiency and funding, registries can improve healthcare, and are likely to prove significantly cost effective.[22]
- Provision of timely, reliable and constructive feedback to clinical teams, and engagement and participation of key stakeholders, such as health system managers and payers, improves the impact of registries.
- Registries can contribute to government initiatives designed to manage rapidly aging populations, and can further help governments to promote the equitable provision of care.[23]

Relationship between clinical guidelines, quality indicators and registries

- **Clinical guidelines** – recommendations informed by systematic review of evidence, designed to optimise patient care.[24]
- **Clinical standards** – derived from clinical guidelines, clinical standards include succinct, quality statements that describe the optimal quality of care a patient should receive, including quality indicators.[25]
- **Quality indicators** – are used to monitor the implementation of quality statements, and identify areas for improvement. Quality indicators are reported by hip fracture registries.[25]

Practical aspects of establishing a registry

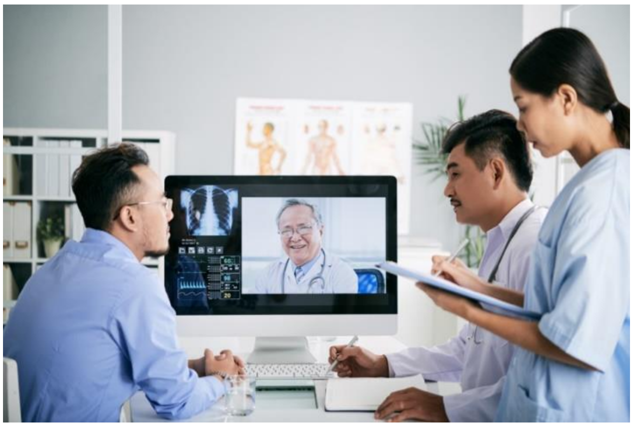
This comprehensive Toolbox arms the user with insights, explanations and guidance on the practicalities of establishing a hip fracture registry, including:

1. **Clinical leadership and engagement:**
    - For the successful development of a hip fracture registry, committed clinical champions with leadership skills are crucial.
    - At the outset, these clinical registry champions should convene a meeting inviting their relevant colleagues and members of national professional organisations and non-government organisations, to join.
    - Invitees could include representatives from national and regional organisations e.g. geriatric and internal medicine, orthopaedic surgery, osteoporosis and metabolic bone disease, nursing, physiotherapy and rehabilitation groups.
    - Outcomes of the first meeting may include:
        - Establishment of a National Registry Steering Group;
        - Garnering learnings and insights from those who have established registries;
        - Review of national clinical practice guidelines relating to acute care, rehabilitation and secondary hip fracture prevention to determine whether clinical standards and quality indicators from the current available guidelines can be utilised, or whether the guidelines require updating; and
        - Identifying suitable individuals to establish working groups focusing on funding, IT, minimum datasets, ethics and governance, and consumer advocacy and feedback.

2. **Consolidating and broadening stakeholder buy-in**
    - Drafting, and ultimately establishing a multi-party Memorandum of Understanding (MoU) is a proven approach to consolidating stakeholder commitment.

3. **Building the case for change**

   A 'why, how, what' approach to rallying for change reinforces the:



- **Why** – evidence and reasons that support the need for a registry;
- **How** – adopting a simultaneous bottom-up, top-down approach on how to establish a registry. The bottom-up approach will encourage early adopters at an institutional level, to create a grassroots movement, while at a macro level, national and non-government organisations can advocate for care improvements, involving a top-down approach.
- **What** – specific action items to enable the establishment of a registry, including identification of funding sources; adopting existing clinical guidelines; clinical standards and quality indicators; developing a minimum common data set;* identifying a technology platform to enable data collection; considering ethics requirements; and establishing a registry implementation group. **Please see definition of minimum common data sets at the end of this backgrounder.*

4. **Registry planning and funding**
   - The Toolbox contains links to the Agency for Healthcare Research and Quality (AHRQ) resources comprising comprehensive information on registry planning and funding.[26]
   - Appendix 5 of the Toolbox outlines proposed agendas for the first 3 national registry steering group meetings.
   - The Toolbox highlights several facilitators and barriers to efficient registry planning and funding.
   - Appendices 2-4 provide detailed accounts of how registries in Australia and New Zealand, Spain and the UK were established, operate, and have received funding as a guide.

5. **A registry pilot and increasing participation**
   - Commonly, registry participation in the early days is low.
   - Appendices 2-4 of the Toolbox include detailed descriptions of approaches to increasing registry participation.
   - The Fragility Fracture Network (FFN) Clinical Toolkit[27] explains how to establish a pilot program within a multidisciplinary hospital team, by benchmarking a clinical standard for hip fracture, and performing an audit. This resource further outlines how to expand the pilot program and ultimately, establish a sustainable service.

6. **Governance and ethics**
   - An initial objective is to establish a Steering Group of individuals representing all relevant professional and non-government organisations.
   - While ethics approval varies from country to country, AHRQ resources linked to within the Toolbox feature comprehensive explanations of registry ethics, data ownership and privacy. Examples of ethics approvals for the established Australia and New Zealand and Spanish registries are included.

7. **Minimum common data (MCD) sets and data dictionary**

   MCD sets are a set of standardised data elements that define and name relevant clinical constructs, designed to optimally represent and capture patient data for a particular condition, procedure, speciality, discipline or healthcare process.[28] The Toolbox recommends that new registries adopt the FFN MCD,[5] a tried and tested dataset, that enables international benchmarking. The definition of each data variable needs to be provided in a data dictionary.

APFFA YouTube Channel

The launch of the Toolbox coincides with the announcement of the new APFFA YouTube channel. This channel will house a series of educational videos featuring interviews with leading clinicians from the Asia Pacific bone arena, reflecting on important considerations for each of the seven key steps involved in establishing a hip fracture registry.

About the Asia Pacific Fragility Fracture Alliance (APFFA)

Formed in November 2018, APFFA comprises 7 global and regional member organisations from the geriatrics, orthopaedics, osteoporosis and rehabilitation sectors, with the primary purpose of driving policy change, improving awareness, and changing political and professional mindsets, to facilitate optimal fragility fracture management across Asia Pacific.

The 7 regional and global member organisations comprising APFFA include the Asian Federation of Osteoporosis Societies (AFOS), Asia-Oceanian Society of Physical and Rehabilitation Medicine (AOSPRM), Asia Pacific Geriatric Medicine Network (APGMN), Asia Pacific Orthopaedic Association (APOA), Fragility Fracture Network (FFN), International Osteoporosis Foundation (IOF) and the International Society for Clinical Densitometry (ISCD).

APFFA's vision is to deliver effective care, fewer fractures and better outcomes for people living in Asia Pacific.

About the APFFA Hip Fracture Registry Working Group

- The APFFA Hip Fracture Registry Working Group is a principal action group within APFFA, comprising global experts in hip fracture treatment and management.
- This Group is charged with leading the development of the Toolbox – outlining the key steps for establishment of a national hip fracture registry.
- In addition, the HFRWG report on hip fracture epidemiology and outcomes across Asia Pacific is designed to frame the problems facing the region and outline APFFA-related projects as a component of the solution to these issues.
- The HFRWG are further responsible for a feasibility study, to scope the costs and practicalities of establishing new hip fracture registries in specific countries across Asia Pacific.

About the Fragility Fracture Network (FFN)

- The FFN is a global organisation founded to create a multidisciplinary network of experts charged with improving the treatment and secondary prevention of fragility fractures.
- The organisation strives to optimise multidisciplinary management of a patient with a fragility fracture, to ensure maximum recovery, quality of life, and no further fractures, worldwide.
- A range of Special Interest Groups (SIGs) sit under the umbrella of the FFN Scientific Committee, including the Hip Fracture Audit (HFA SIG), Hip Fracture Recovery Research, Perioperative Care, Physiotherapy, Vertebral Fragility Fracture and Secondary Fracture Prevention groups.
- The HFA SIG comprises a multidisciplinary network of clinicians well-versed in hip fracture audits, striving for global adoption of a Minimum Common Dataset (MCD) and a worldwide platform to share HFA knowledge, learning and research.
- Both the HFA SIG and the FFN Regionalisation Committee provide networking opportunities for National Registry Champions to share experiences and learn from one other.

To learn more about the Hip Fracture Registry Toolbox, head to www.apfracturealliance.org/HFR-toolbox/

For more information, please contact Kirsten Bruce or Mel Kheradi from VIVA! Communications:
T. +61 401 717 566 / +61 2 421 551 257
E. kirstenbruce@vivacommunications.com.au / melorin@vivacommunications.com.au

References

1. Baker, P.N., et al., *Evolution of the hip fracture population: time to consider the future? A retrospective observational analysis.* BMJ Open, 2014. 4(4): p. e004405.
2. Johansen, A., et al., *Using national hip fracture registries and audit databases to develop an international perspective.* Injury, 2017. 48(10): p. 2174-2179.
3. Currie, C., *Hip fracture audit: Creating a 'critical mass of expertise and enthusiasm for hip fracture care'?* Injury, 2018. 49(8): p. 1418-1423.
4. Wise, J., *Hip fracture audit may have saved 1000 lives since 2007.* BMJ : British Medical Journal, 2015. 351: p. h3854.
5. Asia Pacific Fragility Fracture Alliance. *Hip Fracture Registry Toolbix*. 2021 [cited May, 2021]; Available from: www.apfracturealliance.org/HFR-toolbox/
6. Australia and New Zealand Hip Fracture Registry. *Australia and New Zealand Hip Fracture Registry*. [cited May, 2021]; Available from: https://anzhfr.org.
7. Yamamoto, N., H.E. Takahashi, and N. Endo, *Chapter 6 - The Challenge of Secondary Prevention of Hip Fracture in Japan*, in *Secondary Fracture Prevention*, M.J. Seibel and P.J. Mitchell, Editors. 2019, Academic Press. p. 109-115.
8. Kim, J.W., et al., *Reoperation rate, mortality and ambulatory ability after internal fixation versus hemiarthroplasty for unstable intertrochanteric fractures in elderly patients: a study on Korean Hip Fracture Registry.* Arch Orthop Trauma Surg, 2020. 140(11): p. 1611-1618.
9. Schoeneberg, C., et al., *Effect of time-to-surgery on in-house mortality during orthogeriatric treatment following hip fracture: A retrospective analysis of prospectively collected data from 16,236 patients of the AltersTraumaRegister DGU®.* Injury, 2021. 52(3): p. 554-561.
10. Kristensen, P.K., et al., *The Danish Multidisciplinary Hip Fracture Registry 13-Year Results from a Population-Based Cohort of Hip Fracture Patients.* Clin Epidemiol, 2020. 12: p. 9-21.
11. Sund, R., et al., *Monitoring the performance of hip fracture treatment in Finland.* Annals of Medicine, 2011. 43(sup1): p. S39-S46.
12. Yli-Kyyny, T.T., et al., *Risk factors for early readmission due to surgical complications after treatment of proximal femoral fractures – A Finnish National Database study of 68,800 patients.* Injury, 2019. 50(2): p. 403-408.
13. Walsh, M.E., et al., *Trends in hip fracture care in the Republic of Ireland from 2013 to 2018: results from the Irish Hip Fracture Database.* Osteoporos Int, 2021. 32(4): p. 727-736.
14. Finnish Institute for health and welfare. *PERFECT Hip Fracture Registry* Available from: https://thl.fi/fi/tutkimus-ja-kehittaminen/tutkimukset-ja-hankkeet/perfect/osahankkeet/lonkkamurtuma/perusraportit.
15. Ferrara, M.C., et al., *Three-year National report from the Gruppo Italiano di Ortogeriatria (GIOG) in the management of hip-fractured patients.* Aging Clin Exp Res, 2020. 32(7): p. 1245-1253.
16. van Voorden, T.A.J., et al., *Effect of the Dutch Hip Fracture Audit implementation on mortality, length of hospital stay and time until surgery in elderly hip fracture patients; a multi-center cohort study.* Injury, 2020. 51(4): p. 1038-1044.
17. Kristoffersen, M.H., et al., *Cognitive impairment influences the risk of reoperation after hip fracture surgery: results of 87,573 operations reported to the Norwegian Hip Fracture Register.* Acta Orthop, 2020. 91(2): p. 146-151.
18. The Scottish Hip Fracture Audit. *The Scottish Hip Fracture Audit*. [cited May, 2021]; Available from: https://www.shfa.scot.nhs.uk.
19. Ojeda-Thies, C., et al., *Spanish National Hip Fracture Registry (RNFC): analysis of its first annual report and international comparison with other established registries.* Osteoporos Int, 2019. 30(6): p. 1243-1254.
20. Jc, V., et al., *Mexican Hip Fracture Audit (ReMexFC): objectives and methodology.* MOJ Orthopedics & Rheumatology, 2019. 11: p. 115-118.
21. Arshi, A., et al., *Standardized Hospital-Based Care Programs Improve Geriatric Hip Fracture Outcomes: An Analysis of the ACS NSQIP Targeted Hip Fracture Series.* J Orthop Trauma, 2019. 33(6): p. e223-e228.
22. Australian Commission on Safety and Quality in Health Care, *Economic evaluation of clinical quality registries*. 2016.
23. Australian Government, *National Clinical Quality Registry and Virtual Registry Strategy - A National Strategy for Clinical Quality Registries and Virtual Registries 2020-2030*. 2020.
24. Institute of Medicine Committee on Standards for Developing Trustworthy Clinical Practice, G., in *Clinical Practice Guidelines We Can Trust*, R. Graham, et al., Editors. 2011, National Academies Press (US) Copyright 2011 by the National Academy of Sciences. All rights reserved.: Washington (DC).
25. Australian Commission on Safety and Quality in Health Care and Health Quality & Safety Commission New Zealand, *Hip Fracture Care Clinical Care Standard*. 2016.

26. Agency for Healthcare Research and Quality. *Registries for Evaluating Patient Outcomes: A User's Guide: 4th Edition*. Available from: https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/users-guide.
27. Fragility Fracture Network. *FFN Clinical Toolkit*. 2020; Available from: https://www.fragilityfracturenetwork.org/wp-content/uploads/2020/10/FFNClinicalToolkit_English_v1_web.pdf.
28. Svensson-Ranallo, P.A., T.J. Adam, and F. Sainfort, *A framework and standardized methodology for developing minimum clinical datasets.* AMIA Joint Summits on Translational Science proceedings. AMIA Joint Summits on Translational Science, 2011. 2011: p. 54-58.