

Suffering in silence: Assessing rare disease awareness and management in South Korea

In November-December 2019, The Economist Intelligence Unit surveyed 100 practising healthcare professionals from South Korea, as part of an Asia-Pacific analysis of understanding and challenges faced in managing rare diseases.

Our survey respondents from South Korea comprised general practitioners or primary care physicians (45%), specialist physicians (35%), nurses (10%) and pharmacists (10%). Respondents reported working in predominantly private (58%) and public (12%) or teaching healthcare institutions (25%).

Results in context: South Korea's health system

- South Korea's population was estimated to be 51.2m in 2019.¹ The average life expectancy was an estimated 82 years in 2018, with a modest increase to 83 years projected by 2023. Infant mortality is low, with an estimated three deaths per 1,000 live births. In 2018, South Korea saw its fertility rate fall to an all-time low of 0.98 births per woman, and South Korea is facing a rapid increase in old-age dependency ratio with its ageing population. Non-communicable diseases are the biggest causes of mortality in South Korea, accounting for nearly 80% of deaths. Cardiovascular diseases and cancer are the biggest causes of death.²
- According to OECD data, health expenditure was 8.1% of GDP in 2018, an increase of nearly 8% from 2017. The National Health Insurance (NHI), a government single-payer universal health coverage system established in the late 1980s, covered 51.1m people by the end of 2018, nearly the entire South Korean population. Budget limitations remain an issue for accessing new medicines within the system. In addition, mismatch between reimbursement guidelines and clinical practice guidelines result in insufficient care for some rare disease patients.³
- In early 2018, the government launched a five-year plan to reform the NHI scheme with a view to deepen coverage and subsidise around 3,800 treatments currently only covered by private insurance or out-of-pocket payments. Patient co-payment rates are 20% for inpatient services, and between 30% and 60% for outpatient care, with a total out-of-pocket payment cap set based on income bracket. Private health insurance spending accounted for only 7.4% of total healthcare spending in 2018.²
- There were over 100,000 doctors and around 195,000 nurses registered in 2018, providing 2.4 doctors per 1,000 people. There is a skew towards specialist physicians working in the private sector, with primary health services delivered in the public system.²

¹ United Nations Population Division: World Population Prospects 2019. Estimates 1950–2020.

² The Economist Intelligence Unit. Industry Report Healthcare South Korea. 3rd Quarter 2019.

³ Kii-Young Yoo, *et al.* "Global hemostatic assay of different procoagulant activities of factor VIII and factor IX". *Blood Research* 2018

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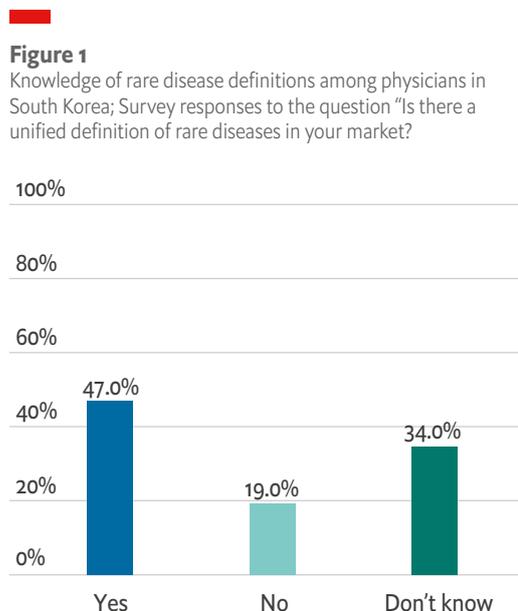
Prioritising rare diseases: Evolving health policy to capture more patients in South Korea

- In 2015, South Korea’s parliament passed the *Rare Disease Management Act*, requiring that the Ministry of Health and Welfare commit to greater research and development of plans for the prevention, diagnosis and treatment of rare diseases.
- In 2017, the Ministry of Health and Welfare released a 2017-2021 road map for the diagnosis, treatment and management of rare diseases. This comprises four strategies around building an evidence base, establishing a basis for diagnosis and treatment, expanding diagnosis and treatment support, and strengthening R&D.
- As a first step, the Korean Undiagnosed Disease Programme (KUDP) was launched as a small pilot programme with a sample group of under 100 patients. This expert, multi-disciplinary consortium of paediatric and adult medical specialists, based at a total of six institutions, acts as a referral board for diagnosing difficult cases. The programme was expanded to cover 11 centres treating such conditions by the end of 2019.
- South Korea’s Rare Disease Management Act defines rare diseases as any affecting fewer than 20,000 people in the country (approximately 3.9 cases per 10,000). It is also notable for its inclusion of conditions with unknown burden due to difficulty in diagnosis.⁴

- More than half of our survey respondents either did not know there was a unified definition for rare diseases enshrined in policy, or incorrectly reported that one did not exist (Figure 1). Among this subgroup, there appears to be some alignment between policy and what healthcare professionals value.

The top three most-cited elements that should be included in a definition of rare diseases were:

- o A disease with an undefined low prevalence (73.6% of respondents).
- o Effect on quality of life or risk of disability (64.2% of respondents).
- o Difficulty of diagnosis (60.4% of respondents).



⁴ Korea Legislation Research Institute. Available at: http://elaw.klri.re.kr/eng_service/lawView.do?hseq=43655&lang=ENG (Accessed Feb 2020).

- When asked about the usefulness of having a rare disease definition, healthcare professionals in South Korea identified facilitating diagnosis and developing new treatments as the greatest advantage. Interestingly, our respondents also saw potential for a definition to aid societal understanding and acceptance of rare diseases (38% rated this as most important on a 5-point scale).

Low confidence in rare disease knowledge among healthcare professionals despite seeing patients more frequently

- Healthcare professionals from South Korea responding to our survey had

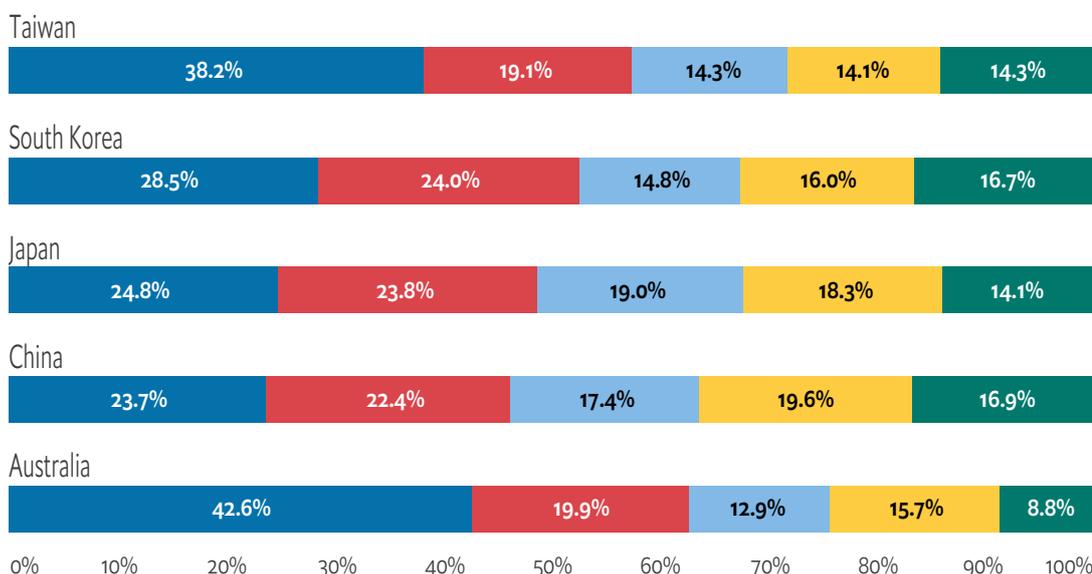
middling confidence in their own knowledge of rare diseases (on average 3.11 out of 5) and that of their peers (average 2.90 out of 5).

- Healthcare professionals in South Korea reported seeing new rare disease patients more frequently than any other markets in our study. 22% see a new patient more than once a month and 28% see a new patient more than once every 6 months. Thirteen percent have never seen a new rare disease patient present for care.

Figure 2

Survey responses reporting average proportion of patients managed with the optimal to sub-optimal care in five Asia-Pacific markets.

- Managed with the best evidence-based care
- Not managed with the best evidence-based care due to lack of clinical practice guidelines
- Not managed with the best evidence-based care due to lack of regulatory approval of medicine
- Not managed with the best evidence-based care due to lack of funding for testing/treatment
- Not managed with the best evidence-based care for other reasons



Increased national collaboration to overcome challenges in rare disease care

- Respondents to our survey report that on average 29% of cases are managed with best evidence-based care (Figure 2).
- Respondents from South Korea, identified initiation of care, cost of care, and providing social care as the weakest elements of their health system's response to rare diseases.
- Multiple areas were cited as challenges when diagnosing and managing rare diseases, most notably:
 - o Reaching the correct diagnosis (72.4% report this is nearly always or is always a challenge).
 - o Access to medicines (58.6% report this is nearly always or is always a challenge).
 - o Patient group support (51.7% report this is nearly always or is always a challenge).
 - o Access to ongoing professional training (52.9% report this is nearly always or is always a challenge).
- When our survey respondents were asked about the one action that should be taken to improve the lives of rare disease patients in South Korea, the most common responses were:
 - o Increased and consistent financial support.

- o Enhanced national collaboration for diagnosis and management.
- o Professional development, training and placement programmes.

Despite low awareness of patient organisations, potential merit is seen in budgeting decisions

- 35% of respondents did not know if there are rare disease organisations active in South Korea. 13% incorrectly reported that none are active.
- Our respondents suggested they wanted to see more activity from patient groups in all areas. Notably, promoting disease awareness and providing patient education and support were valued by more than 80% of respondents.
 - o Respondents were keenly aware of the potential for patient groups to have a voice in decisions on budget distribution or insurance coverage. This was deemed less valuable in other markets of our study, but 75% of South Korean respondents felt patient groups should do more in this area.
 - o In addition, 73.1% of our respondents felt patient groups had a bigger role to play in providing screening or genetic counselling services—the highest proportion in any of our markets studied.