Chronic and rare diseases present unique but equally pressing challenges for public health. Together, they are the leading causes of morbidity and mortality in North America, and place a major burden on healthcare resources and economies. However, when it comes to cure and prevention they demand very different lines of attack.
What’s in a name?

There is no single, universally accepted definition of what constitutes a rare disease. They are often referred to as, ‘orphan diseases’ due to a shared lack of awareness, resources and treatments.

A disease can be defined as ‘rare’ if it affects fewer than:

- 1 in 1,500 people in the US
- 1 in 2,000 people in the EU
- 1 in 2,500 people in Japan

A chronic disease is defined as a disease lasting three months or longer.

They are not passed from person to person and are also known as non-communicable diseases (NCDs).

A serious problem

Almost 7,000 different rare diseases have been identified worldwide affecting 350 million people.

If all of these people lived in one country, it would be the 3rd most populous in the world.

Chronic diseases affect approximately 45% of the US population.

Each year, deaths due to chronic diseases account for:

- 70% of US deaths
- 89% of Canadian deaths

which represents 63% of all deaths worldwide.

References:
1. US Rare Diseases Act of 2002
2. EU Commission on Public Health
4. US National Center for Health Statistics
5. World Health Organization (WHO)
6. Centers for Disease Control and Preventions (CDC)
7. US Department of Health & Human Services
8. National Institutes of Health (NIH)
9. The Global Genes Project
10. Ibid
11. US National Health Council
12. American Public Health Association (APHA)
14. The EveryLife Foundation for Rare Diseases
Demographics

- **80%** of rare diseases have a genetic basis. For this reason, they disproportionately affect children.
- Children make up **50%** of rare disease patients.
- Of these young patients, **35%** do not survive to see their first birthday, and **30%** do not live past the age of four.
- About **14%** of adolescents suffer from a moderate or severe chronic condition.
- As many as **75%** of Americans aged 65 years and older have MCC.
- Still, nearly **95%** of rare diseases do not yet have an FDA-approved drug treatment.
- Furthermore, approximately **50%** of rare diseases are not supported by a disease-specific foundation.

Chronic diseases affect people of all ages, ethnicity and wealth.

- Approximately **1 in 4** Americans have multiple chronic conditions (MCC), including **1 in 15** children.

Development and cost

The Orphan Drug Act was passed in the US in 1983. The Act promotes the development of drugs for the treatment of orphan diseases by reducing statistical burdens, introducing financial incentives, subsidising clinical research and enhancing marketing rights and patent protection.

- For example, a pharmaceutical company can sell its novel orphan drug without competition for **seven years** after release.

When the Act was first established in 1983, only 38 Food and Drug Administration (FDA)-approved orphan drugs existed.

By 2010, 353 novel drugs for the treatment of orphan diseases had been approved by the FDA, and 200 different rare diseases had become treatable.

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- A **2%** annual reduction in Canadian chronic disease death rates over 2005-15 would have resulted in an economic gain of CAD **$1 billion**.

- **Four modifiable health risk behaviours** are responsible for a significant proportion of chronic disease morbidity and mortality:
  - lack of physical activity
  - poor nutrition
  - tobacco use
  - excessive alcohol consumption

- The **Affordable Care Act** passed in 2010 included the formation of the Prevention and Public Health Fund (PPHF) to provide for expanded and sustained national investment in prevention and public health programmes to improve health and help restrain the rate of growth in private and public healthcare costs.

- The PPHF has since provided **$2.25 billion** for prevention and public health activities. However, this is only **3%** of total US healthcare spending.

- **7 out of the 5** most expensive health conditions are chronic conditions.

- **75%** of US healthcare costs are due to chronic conditions.