# Making Healthcare Better Through Data: A Journey Beyond Numbers

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## Data Science in Rare Diseases: Insights from a Pompe Disease Data Project

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## What is Pompe Disease?

Pompe disease is a rare inherited condition where the body can not properly break down sugar stored in the muscles. It comes in two forms: one that affects babies (Infantile-Onset) and another that can develop at any age (Late-Onset)

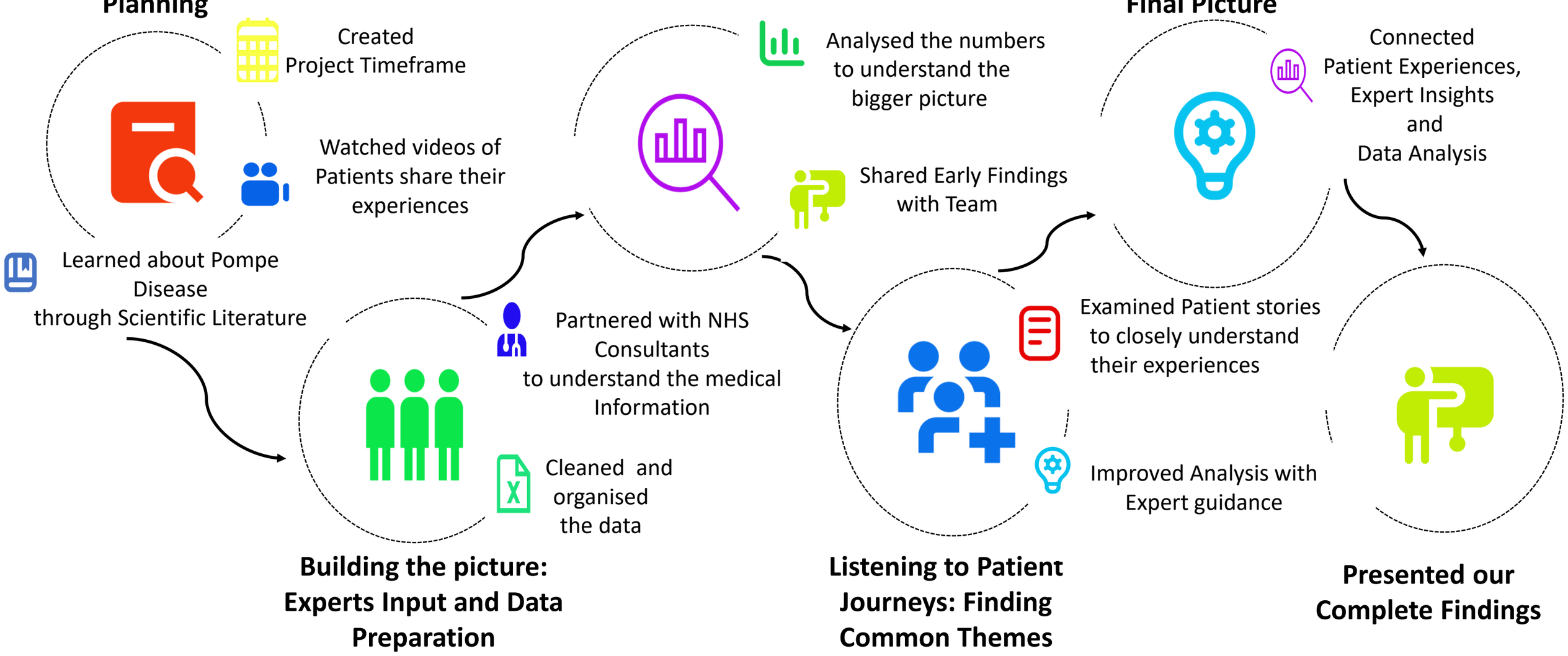
## Why does it matter?

Pompe disease is associated with long diagnostic delays. It is often misdiagnosed because its symptoms mimic common illness. These symptoms can vary from weakness, fatigue to breathing and heart issues. Therefore, finding the gaps in patient journey is important for helping doctors recognise the disease earlier and potentially save lives

## My Project Focus

Understanding how we can help people with Late-Onset Pompe Disease get diagnosed sooner by looking at their healthcare journey

## How I Worked: Mixing Data Skills with People Skills




## Key Learnings

- Mastered the act of tailoring communication to different audience
- Learned to take initiatives and prioritise tasks
- Learned to analyse data with a solution-driven mindset as opposed to an information-generation mindset
- Gained a better understanding of how the Pharmaceutical Industry works
- Learned the importance of a patient-centred analysis

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## References

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